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At the Intersection of Socio-Legal and Science & Technology Studies

*Edited by **Emilie Cloatre, Martyn Pickersgill***

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Knowledge, Technology and Law examines the interface between studies of law, science and society, from the perspectives of socio-legal studies and science and technology studies (STS). The relationships between law, science and society are central to a diverse range of practical, ethical and theoretical issues. With an increasing emphasis on the fluidity and uncertainty of each of these areas, the analysis of their intersection(s) has become complex. Accordingly, scholars have borrowed from a range of disciplines and case studies to analyse not only how such intersections materialize, but also how and from where they should be approached. Notably, STS has provided a basis to explore the links between science and society, and socio-legal studies has offered many tools to understand the relationships between law and society. In recent years, a growing number of scholars have borrowed from both fields in order to further their efforts to understand the interconnectedness of law, science and society. This collection charts the important interface between studies of law, science and society, as explored from the perspectives of socio-legal studies and the increasingly influential field of STS. It brings together scholars from both areas to interrogate the joint roles of law and science in the construction and stabilization of socio-technical networks, objects, and standards, as well as their place in the production of contemporary social realities and subjectivities.

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The voice of silence: UK patients' silent resistance to the assisted reproduction regulations

Ilke Turkmendag*

Abstract

This chapter examines the role of patient support networks in generating forms of resistance and enhancing engagement in the governance of assisted reproduction technologies in the UK. From 1 April 2005, UK law was changed to allow children born through gamete donation to access identifying details of the donor. For a majority of fertility patients, this also meant that they came to find themselves on lengthy waiting lists due to donor shortages. Perhaps surprisingly, the voices of would-be parents - those who would be most affected by a contraction in donor supply - were not heard during the donor anonymity debate or thereafter. The would-be parents' reluctance to mobilise around pressing claims against the removal of donor anonymity partly reflects the variety of ways in which they can avoid the impact of this legislation. Many fertility patients in the UK used online discussion forums hosted by patient support networks to show their reactions to the new law. These discussion boards were snowed under with posts about treatment opportunities in other jurisdictions, and the purchasing of sperm online. Support networks not only provided would-be parents with a forum to rehearse concerns about the law, but also enabled them to develop strategies to circumvent the limitations it imposed upon their reproductive freedom. The UK should take full advantage of the Internet and information technology to enhance stakeholder participation.

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Introduction

Since the 1990s, one of the most controversial changes to the UK's Human Fertilisation and Embryology Act (HFE Act) concerned the information that is kept about the egg, sperm

(gametes) and embryo donors in donor registers. This information is held by the Human Fertilisation and Embryology Authority (HFEA), which is a quasi-autonomous non-governmental organization (quango) set by the HFE Act in 1990 to license and regulate clinics that carry out *in vitro* fertilisation (IVF), other assisted conception techniques using human sperm, eggs and embryos, and embryo research.

Originally, section 31(3) of the HFE Act 1990 allowed offspring conceived through gamete donation the right to apply for information about the donor when reaching the age of 18. In practice, donors were asked to provide some non-identifying information, which could be passed to potential recipients. However, on 1 April 2005, with the implementation of the *Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulations 2004*, UK law was changed to allow children born through gamete donation to access identifying details of the donor.¹ Drawing on trends in adoption law the decision to abolish donor anonymity was strongly influenced by a discourse that asserted the ‘child’s right-to-personal identity’, encouraged by the European Convention on Human Rights (ECHR)².

The removal of donor anonymity has aggravated the outgoing donor shortage since individuals were less likely to donate if their relatedness could one day be established.³ Moreover, on 5 July 2007 the HFE Act was amended in order to bring the EU Tissues and Cells Directive (EUTCD) into UK law.⁴ The implementation of EUTCD’s voluntary and unpaid donations policy for tissues and cells has made it even more difficult to recover the donor shortage as donations cannot be promoted by financial incentives.⁵ As a result, fewer people now have access to the treatment in the UK.

Perhaps surprisingly, neither during nor after the removal of donor anonymity did the government face organised resistance from would-be parents through classic avenues of opposition to new legislation; i.e, both those who cannot receive treatment due to the donor

¹ The Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulations 2004 SI 2004/1511.

² I Turkmendag, ‘The Donor-conceived Child’s “Right to Personal Identity”: The Public Debate on Donor Anonymity in the United Kingdom’ (2012) 39 *Journal of Law and Society* 58. European Convention for the Protection of Human Rights and Fundamental Freedoms 1950, ETS 5. The ECHR was incorporated into domestic law in the UK via the Human Rights Act 1998.

³ Turkmendag, Dingwall and Murphy (n 2)

⁴ Directive 2004/23/EC of the European Parliament and of the Council of 31 March 2004 on setting standards of quality and safety for the donation, procurement, testing, processing, preservation, storage and distribution of human tissues and cells [2004] L 102/48. There are also two supplementary Technical Directives: 2006/17/EC; 2006/86/EC.

⁵ I Turkmendag, ‘When Sperm Cannot Travel: Experiences of UK Would-Be Parents Seeking Treatment Abroad’ in ML Flear, A-M Farrell, TK Hervey and T Murphy (eds), *European Law and New Health Technologies* (Oxford University Press, 2013).

shortage, and those who might carry the burden of informing children of their origins if treatment were available and successful.⁶ Those who prefer anonymous donation are reluctant to press their claims because confidentiality matters to them.⁷ Even those who are pro-openness may be reluctant to face publicity as undergoing fertility treatment, and using donated gametes are private matters. Presumably because they did not articulate their concerns in formal ways of communication (such as lodging complaints for a policy change), there has been little enquiry into the reactions of would-be parents to the new law. But, despite their reticence during the donor anonymity debate, would-be parents articulated *anonymous* protests against the new law on the discussion forums of online fertility support groups. In this chapter I examine such discussion forums in order to cast fresh light into the discourse of would-be parents that was propelled by the change to the HFE Act. I examine how strategies of legal avoidance and resistance to the new law were facilitated by the growth of an online community of would-be parents, and explore their impact on policy adjustments. The data form part of my on-going (since 2005) research into the socio-legal dimensions of reproductive care.

Avoidance of the Law by the ‘Virtual’ Patient Communities

Online forums are known to have transformed much of the movements and relationships that animate communities of would-be parents. As an example, Waldby (2008) argues that multilingual websites and Internet communication have made international partnerships and the possibilities for patients to travel abroad for treatment much easier. This, together with the legal possibilities offered by the European Union, have facilitated what is sometimes referred to as ‘cross border reproductive care’ (CBRC): a form of medical tourism that enables patients to take advantage of differences in reproductive consumer cultures reflected in variations in the cost and availability of treatments, success rates, and waiting lists. The removal of donor anonymity in the UK, has resulted in an increasing number of would-be parents abroad to seek treatment, a movement facilitated by the availability of online support that Waldby describes.⁸ Indeed, the internet plays a significant role here, that I retrace through this chapter: through online discussion forums, it facilitates ongoing discourse among

⁶ Turkmendag, Dingwall and Murphy (n 2)

⁷ Ibid.

⁸ F Shenfield et al, 'Cross Border Reproductive Care in Six European Countries' (2010) 25 Human Reproduction 1361.

the patients, effectively creating a ‘virtual patient community’, a social aggregation based on common interest and intellectual and affective (rather than geographic) proximity. The virtual patient community that emerged around (and in antagonism to) the changes to the HFE Act did not promote the breaking of law, but instead its avoidance. Community members develop and share strategies to do this (i.e., how best to make use of CBRC), and mobilise around their contentions about the legal shift whilst remaining anonymous.

In the UK the online discussion forums hosted by fertility support groups (e.g. *Acebabes*, *fertilityfriends*, *INUK*, *More to Life* and *IVF.Net*) or fertility clinics played a salient role (perhaps unintentionally) in helping potential patients to overcome their anxiety about receiving treatment away from home. Following the removal of donor anonymity, these forums were snowed under with posts about treatment opportunities in other jurisdictions. Those who wanted to receive treatment using anonymous gametes and those who were denied access to treatment at home for various reasons (donor shortage, being regarded as unfit parents) exchanged information about the jurisdictions where the treatments they needed would be available (e.g. standards of the clinics, the success rates, costs, quality of the aftercare, whether practitioners or nurses could speak English, and regulatory frameworks). Those who could not afford to travel abroad exchanged information about ‘backstreet’ arrangements (such as purchasing of sperm online). In addition, these forums became a space in which patients could express their opposition to the new law without making their identities known (e.g. signing online petitions, discussing the HFEA’s decision-making processes, sending feedback through forum administrators, talking to journalists and researchers.). In what follows, I present data collected during a virtual ethnography on one of these discussion forums: *Repromed* (www.repromed.co.uk), which was hosted by the website of the Bristol Centre for Reproductive Medicine (BCRM).⁹ In doing so, I render visible the discreet ways in which would-be parents avoided, resisted, and ultimately expressed their opposition, to the new law.

‘Would-be’ parents and the discussion forums of Repromed

Repromed introduced itself as a website for anyone in the UK interested in reproductive medicine. Like many other patient support groups, *Repromed* was open to anyone, at any

⁹ At the time of this study, the clinic behind the Repromed website was the University of Bristol’s, Centre for Reproductive Medicine. This centre has now merged with the Southmead Fertility Service.

stage of their treatment, offering an ideal platform to access to information about treatment techniques, clinics abroad, and other patients' experiences at no or little cost (some patient groups may require a small subscription fee), quickly and anonymously from home. On the home page there was a link to the discussion area; there, the forum titles were listed. Each topic involved a question, or a brief introduction about the inquiry; for example: "Is anyone currently trying or pregnant with a donor conceived baby?" Forum administrators and moderators, who had the highest level of control over forum content, could turn forum features on and off, ban and remove users, edit and delete posts, and create users and groups. This gave them some control over the postings, although it might be rather difficult to monitor and manage such a large and continuously evolving content. By the time that I visited the website in 2006, users had posted 27,829 messages, on 704 topics, in 15 forums. The age range of the other 28 users was from 28 to 43. The average age was 35 and there were two modes (the most frequently occurring age in the distribution) at 35 and 40. Although more than 5000 postings were scanned, the final sample included 900 postings sent between 13 July 2005 and 26 April 2007.

Posts on *Repromed* included inquiries as to where one could receive treatment abroad by using gametes from anonymous donors, stories about fertility travel, complaints about the long waiting lists and the donor shortage in the UK, and criticism of the new regulations. The data presented here draws mainly on the 'Donor Gamete' Forum on *Repromed*, which had the fullest coverage of donor anonymity. Although this study does not claim to be a definitive account of UK would-be parents who use online forums, *Repromed* was clearly one of the most active sites (based on the number of messages posted, and the depth of the threads) during this period and represents an important source of data on voices that were not fully heard in the public debates over ending donor anonymity. The extracts from the forum posts that I present herein are not edited, except for the references to clinics or names of websites where sperm can be purchased.

Policy Processes and Patient Reactions

Before this forum was set up, fertility travel was being addressed in other discussion forums on the website. One of the patients, Elaine, who was receiving treatment at the BCRM (the clinic that hosts *Repromed*), had decided to receive treatment in Spain; this was mainly due to

the removal of donor anonymity in the UK and consequent lengthening of waiting lists. She shared her experiences with other users of *Repromed*, eventually meeting in person and befriending six other women users who also ended up receiving treatment in Spain. According to Elaine, the fact that they were discussing their experiences on *Repromed* discussion forums was not well-received by the host clinic and the administrator set up a new 'Donor Gamete' forum so that people receiving donor gamete treatment could interact in a setting separate from other patients of the clinic. It was established in November 2005 with the following disclaimer:

After much discussion we have set up the Donor gamete forum. We are a little concerned about the overseas fertility treatment options as these are outside UK ethical and safety regulations, but we fully agree that UK patients receiving donor gamete treatment would benefit from mutual online support.

Regards, Admin

Most forum participants were on waiting lists for gamete donation and clearly associated the donor shortage with the change in the law to remove anonymity. Examples of posts expressing this view were as follows (all are excerpted from a thread about the options available for those who attempted to receive treatment in licensed clinics in the UK but for various reasons could not access the treatment they need):

Apparently out of 500 applicants to give sperm in the last year only 2 actually do so, predominantly due the anonymity issue and the low sperm counts of the younger applicants. Very frightening stats don't you think? (Mandy)

i do think that the change in the law has got every thing to do with it especialy if you are donating eggs or sperm and you are haveing difficulty consiving yourself .i have also been told that sperm donations have gone down because there use to be alot of students that use to donate but have stoped because they dont want a knock on the door in 18 years do you know if it the same if you go out side theuk and have treatment and donate at the same time cause im not sure about that one from the first

time i went for icsi to now things seame to have got more compucated and expensive lol (Sheila).

Prior to the removal of donor anonymity, a 2004 Department of Health survey of UK fertility clinics indicated widespread agreement that lifting anonymity would decrease donations.¹⁰ During the spring of 2004, the HFEA conducted its own survey of clinics to develop a detailed understanding of the current demand for, and provision of, treatment using donated gametes or embryos, as well as to identify relevant trends.¹¹ The removal of donor anonymity was the most frequently cited factor anticipated negatively to affect sperm and egg donation by the clinics which were already suffering from a donor shortage. In other words, the donor crisis was hardly a surprise to the regulatory bodies.

In the following post, one user, Tara, drew attention to that the HFEA ignored the evidence provided by the clinics:

They (HFEA) should have warned clinics to overstock a year ago in case this should happen. From what I could gather from the clinics I rang they had warned the HFEA that this would happen!! The HFEA knew there could be a dip in donors as this happened in Australia and New Zealand and Sweden, I would like to know if they ever recovered!! All I can say is well done (not) HFEA (Tara).

If the donor shortage was predictable why then did HFEA take precautions? In 2007, the Department of Health and the National Gamete Donation Trust (NGDT) launched the 'Give a Toss' campaign to raise awareness of donation and recruit new donors (critics of which campaign have accused the NGDT of alienating donor parents, would-be parents and donor-conceived children by perpetuating a 'tacky' image.)¹² Other campaigns were launched throughout the country to promote sperm donation and the British Fertility Society established a working party to examine sperm donation in the UK. Its report was launched at

¹⁰ Donor anonymity to be removed in UK. 242 *Bionews* 2004 <http://www.bionews.org.uk/page_11833.asp> accessed December 2012.

¹¹ Human Fertilisation and Embryology Authority Sperm, Egg and Embryo Donation (SEED) policy review: Findings of the clinic survey.< http://www.hfea.gov.uk/docs/Clinics_survey_Seed_review.pdf> accessed 18 November 2012.

¹² McVeigh, K. Online ads for sperm donors called offensive. *Guardian News and Media Limited* 2007 <<http://www.guardian.co.uk/media/2007/mar/26/newmedia.advertising>> accessed June 2012.

a HFEA meeting in February 2008. The report made a number of recommendations about how the existing pool of donors could be used to more effect: “the report gives a helpful impression of the current state of sperm donation services in the UK, showing an undeniable mismatch between supply and demand”. The HFEA’s response in July 2008 was that the Authority’s remit did not extend to the recruitment of donors; this was a matter for the sector and should be addressed as a matter of urgency.¹³

During the donor anonymity public debate The HFEA made it clear that it supported lifting the anonymity. The then chair of the HFEA, Suzi Leather noted that ‘[W]e have been asking for this for a long time. I can understand why people want to know who their genetic parents are’.¹⁴ In the following post Tara expressed her anger about the view that the child’s right to know should be championed at any cost, rather than weighed against the competing interests of would-be parents:

Anyway on another note we should thanks Dame Suzi Leather and her syndicate for causing this mess!! I wouldnt be surprised if a couple took them to the court of human rights – essentially they are stopping couples having a baby!! To me thats enfringing on our human rights. Of course this is my personal opinion, but I havent yet found anyone who is happy with what the HFEA have done (Tara).

One forum user, Sylvia, claimed that in order to resolve the sperm shortage the law should be changed back; she believed that anonymity should be reinstated, and produced a petition to that effect:

if you think sperm donors should be legally allowed to remain anonymous please sign my petition. i am petitioning the prime minister of the uk to change the law so sperm donors can go back to being anonymous so the sperm shortage can be resolved. if you agree with this please sign at the following link: <http://petitions.pm.gov.uk/sperm-donor-anon/> (Sylvia).

¹³ L Jardin, ‘BFS report on sperm donation in the UK: HFEA response’ (Human Fertilisation and Embryology Authority 2008)

¹⁴ S Leather, ‘Sperm donors to lose anonymity. BBC News, 21 January 2004’ (BBC News, 2004)

Like Tara, she framed the legislative changes as explicitly curtailing her and others' reproductive freedom:

i think anonymity should be brought back after watching a documentary on it. being someone who possibly may need a sperm donor's help in the future id rather not be waiting for years because of the shortage if you agree could you please sign my petition. i understand the reasons why it shouldn't but why should we prevent a loving couple from having the child they wish to have?
come on sign it if you agree :D (Sylvia).

In her response to Sylvia's post, Dorothy says:

I have signed your petition as I have used sperm donor in the past and though we were not successful I was shocked for other people at the huge decline in donors when the law was changed. (Dorothy)

Signing petitions is one of the ways that patients can lodge formal complains. However, it might be problematic for those who have confidentiality concerns. For example, one of the users, Hannah had twins through surrogacy arrangements in USA and did not want this to be known. According to UK law, the surrogate is considered a child's legal mother.¹⁵ If the origins of the twins were known, Hannah would have to formally adopt them in order to become legally recognised as their mother. Hence, she was very careful about making formal complaints that might reveal the origins of her children. Another user, Cheryl opted for adoption after failed attempts to achieve pregnancy. She also had confidentiality concerns about making herself known as she did not know how that would affect her chances of adopting a child.

In order to circumvent the challenges imposed by the law, many would-be parents claimed that they or others might or would go abroad in order to obtain treatment. As Tara put it:

¹⁵ The Human Fertilisation and Embryology Act 2008 section 33 (or the equivalent HFE Act 1990 section 27 for conceptions before 6 April 2009) provides that the woman who gives birth to a child is the legal mother.

Now it has happened, where and what do people needing donor sperm do??? If clinics dont start recruiting their own donors then we will have to go to the ends of the Earth to try and get one, thats our only choice, its so unfair (Tara).

Some commentators consider CBRC as a ‘reproductive exile’ where patients who are denied access to treatment at home are led to find a legal regime under which the treatment they need will be available.¹⁶ For example, in Ireland, where abortion is not permissible unless there is a risk to the pregnant woman’s life, between January 1980 and December 2010, at least 147,912 women travelled from the Republic of Ireland to terminate their pregnancies abroad.¹⁷ Often due to the complicated travel arrangements these abortions are performed later than is preferred, creating emotional upset for women at an already stressful time.¹⁸ Further, only those who can afford to travel can escape the law’s strictures. Again, in Ireland, both illegal abortions, and the use of illegal abortion pills have become a necessity for women who cannot travel abroad to end their pregnancies.¹⁹ Similarly, in *Repromed* discussion boards, some of the users ask for others’ opinions about ‘backstreet’ arrangements:

I have found this company on the web and wanted to know your views: [the web-site’s URL] Having quickly read it through it seems as tho they send you the sperm and you self inseminate (!) for under £400. I know people have been going abroad, but i can't find a place that does D IUI (Suzanne).

In one reply, Tara says:

Also there is another site [the web-site’s URL] as anyone thought or used this one???
I have heard they are fairly good. I have to say it makes me wonder whether all the

¹⁶ R Matorras, ‘Reproductive Exile versus Reproductive Tourism’ (2005) 20 Human Reproduction 3571.

¹⁷ Irish Family Planning Association website.

¹⁸ *ibid.*

¹⁹ S McGuinness, ‘A, B, and C Leads To D (For Delegation!): *A, B and C v. Ireland* 25579/05 [2010] ECHR 2032’ (2011) 19 Medical Law Review 476.

sperm donors that went through clinics and wanted to remain anonymous are now going to these places in order to help people needing it??!(Tara).

Elaine advises this user to seek treatment in Spain using a cheap airline:

Try xxx [a clinic in Spain]- anonymous donor sperm is 260 Euros per go and I flew from Bristol to Barcelona for £50 each way! (Elaine).

In another post, after complaining about the fees that each couple has to pay to undergo treatment, Tara addresses the risks of ‘backstreet’ arrangements. She notes that the new law leads people to consider less legitimate ways of overcoming their childlessness and to take health risks. For example, one can use the ‘turkey baster’ method and achieve pregnancy using fresh sperm, but this sperm cannot be screened for certain diseases. Licensed clinics are required to freeze and store the sperm for six months, the incubation period of HIV, before insemination to ensure that it is virus free.

basically they are ruining couples (like us) chances of having a child using donor or want for a better word 'harder'- they are actually going to force this underground. Couples will go to other agencies (not so legitimate) and abroad to get donors is that fair??? The sad thing is that the women like us may not have as much in the way of protection against certain things like HIV etc I really think they have made the whole donor issue a lot worse (Tara).

Patients seem to be aware of risks involved in purchasing sperm online hence they consult each other about the safety of providers. However, further legislative changes have curtailed even their ability to (legally) assess and respond to such risks themselves. Following the implementation of EUTCD within the UK, Internet sperm providers came to be subject to the same rules as HFEA licensed clinics. Thus, the procurement, testing, processing or distribution of any embryo or gametes intended for ‘human use’ must now be licensed by the HFEA or be subject to an agreement with a licensed service. Therefore, even if would-be parents would like to take a risk with fresh sperm, they have to think twice. The current Chair of the HFEA, Professor Lisa Jardine, has “strongly” advised “any person who became aware

that a person or organisation may be procuring, testing, processing or distributing gametes without a licence to contact the police”.²⁰

On the other hand, if patients are considering obtaining sperm, eggs or embryos from within the EU, a licensed UK clinic can organize for a transfer to be made from that country. However, the sperm, eggs or embryos transferred must meet UK requirements. Would-be parents can also exercise their rights to travel within the EU to receive gametes or embryos from a clinic even if that clinic does not comply with UK standards.²¹

Hence, would-be parents feel that the changes made to the HFE Act enjoins them to seek treatment abroad. One forum user, Suzanne, was a patient at a clinic which found a donor for her; however, he did not match either her physical characteristics or those of her husband. Suzanne and her partner thus chose a donor profile from Spain, to be imported by their licensed clinic, but the clinic informed them that UK law prohibited the purchase of sperm from an anonymous donor. If would-be parents cannot purchase anonymous sperm online, or have the sperm imported by a licensed clinic, they construct themselves as having no option but to go abroad for treatment. Other reasons behind reproductive travel are addressed in the following post by Elaine:

In the end, I think more and more people will go to Europe for treatment, as it costs the same, is completely anonymous, has no waiting lists and, best of all, not bl**dy HFEA!!! That's not to say they aren't regulated, but by sensible people with our interests at heart!!! (Elaine).

The following post by Tom summarises many of the issues raised by other users:

There are many infertility newsgroups out there, so it becomes quite easy to compare the approaches taken by different clinics. Some UK clinics seem to be several steps off the pace of both other UK centres and overseas centres. Treatments used almost routinely in other centres are dismissed with the excuse that it is not current clinic policy, or the treatment isn't proven. The result is that the patient feels that they are

²⁰ L Jardine, 'Internet sperm providers are illegal' (*Guardian News and Media Limited* 2008) <<http://www.guardian.co.uk/uk/2008/sep/23/ukcrime.law1>> accessed 23 May 2012

²¹ Under the directly effective freedom to provide and *receive* services under Article 56 Treaty on the Functioning of the European Union: *R v Human Fertilization and Embryology Authority, ex parte Blood* [1997] 2 All ER 687 (CA). See T K Hervey, 'Buy Baby: The European Union and Regulation of Human Reproduction' (1998) 18 *Oxford Journal Legal Studies* 207.

not being treated as an individual, and they are left with many unresolved questions about their particular situation, and they are paying a premium price for this unsatisfactory state.

In many cases patients find that they are managing their own treatment, pushing the medics to try something outside the standard for that clinic. This is probably the most wearing part of treatment for infertility, dealing with a system that you are not part of. It is probably also the reason why many more women in the UK will turn to overseas centres.

Overseas treatment will also be favoured because any form of medical treatment in the UK means that at some stage the patient will come up against the NHS, a hugely expensive medical insurance scheme which has now turned into a useless quivering jelly of administrators, processes and targets; fertility treatment is way down the list of priorities (Tom).

The accounts I have presented indicate that forums users had significant difficulties in accessing the treatment they sought; this was deemed to be due to the donor shortage, which was itself accounted for as a consequence of legislative change. Following the removal of donor anonymity, would-be parents who could not access treatment due to the donor shortage, and/or preferred anonymous donors constructed themselves as having no choice but to seek treatment abroad or purchase gametes (sperm) through the Internet.

Although discussion forums on online support groups are - in theory - rather democratic places where people can express their opinions freely, they are still subject to control by forum moderators. The power of the moderators was exercised when, in May 2006, *Repromed's* 'Egg and Sperm Donation' forum was suspended. This action followed the HFEA's warning against reproductive care abroad. In April 2006, the then chair of the HFEA, Suzi Leather, issued a public statement warning British citizens against the poorly regulated treatment in overseas clinics:

We know that a relatively small number of people choose to travel abroad to undergo fertility treatment and that sometimes the treatment is packaged as a "holiday" where the patient can convalesce in the sun. However, we are concerned about people who choose to have their treatment abroad should know about the potential risks. (...)It is

very sad when we receive complaints from patients about their treatment abroad and we are not able to help or reassure them. **We would urge patients to think twice and consider the risks and implications before going abroad for treatment.**²² [emphasis added].

The *Repromed* administrator informed me that the 'Egg and Sperm Donation' forum had been closed because members of the HFEA-licensed centre hosting the site were concerned about the increasing number of posts advising participants about offshore facilities for assisted conception using anonymous gametes. The forum was reopened five months later with a disclaimer stating: "In view of popular demand the donor gamete forum has been reopened, but anyone thinking of going abroad for treatment should first consider the guidance provided by the HFEA, which is quoted below." The HFEA's warning about fertility treatment abroad and Leather's speech were both quoted. *Repromed* users posted a range of responses to the disclaimer, expressing discontent about the HFEA's approach to fertility travel:

I'd like to see the HFEA or perhaps other organisation carry out a full investigation into the standards of clinics abroad, to provide some hard evidence that will allow potential patients to make their minds up once fully informed (Will).

I do think the HFEA is very heavy-handed in its approach to this issue, and has also made some very poor regulatory decisions (especially about donor anonymity, for example) which may well end up encouraging people to seek treatment elsewhere. I guess they would open to considerable criticism if it could be shown that, in order to avoid the consequences of their approach, lots of people are travelling abroad for treatment, so now they are trying to discourage them with 'scare tactics'. Not a very grown up approach, really (Melissa).

I feel that if donor anonymity was guaranteed in the UK you wouldn't be going to abroad anyway. That's down to the government perhaps in places they shouldn't (Gemma).

²² S Leather, 'Press Release: Thinking of Going Abroad? Think Twice About Going Abroad for Fertility Treatment' (HFEA 2006) < <http://www.hfea.gov.uk/632.html> > accessed 23 May 2012.

Some individuals grounded their critique of the HFEA with reflections on the high quality treatment they had received abroad; in so doing they (re)positioned foreign clinics not as sites of risk and uncertainty, but as morally progressive and highly professional centres of care:

I really do get fed up with the HFEA scaremongering about going abroad, especially when they've done so much to prevent successful treatment in the UK, for example, removing donor anonymity and successfully wiping out the entire UK sperm bank in one go!!!!!!I for one can only express my utmost admiration at the extremely expert and professional treatment I received at [name of the clinic], which was vastly better than the treatment I received in the UK and resulted in my gorgeous baby at the first attempt. In total, six of us became pregnant after only one or two transfers after going to [name of the clinic], two with twins, which would never have happened if we'd remained in the UK. I think that says it all! (Elaine)

On the note of the HFEA 'warning' all I will say is that I was offered a very high quality individualised treatment at xxx in Spain. I very carefully researched a number of clinics abroad as there were no further options left for me in the UK - I did not have 5 years to wait for Egg Donation in the UK. I was offered a service and support at xxx that was not on offer at any of the three clinics I was under in the UK. Will, I agree whole heartedly with you - it would be good for the HFEA to produce some good statistical evidence of what they claim - I'd like to know just how many people have complained to them about treatment abroad (Kelly).

The HFEA's warning about the risks of off-shore treatment - including countries which were popular EU destinations where assisted conception is highly regulated and standards of fertility clinics are demonstrably as high, if not better, than those in the UK - seemed to have frustrated the would-be parents; they saw themselves as having no choice but to seek treatment abroad as a consequence of the legal shift promoted by the HFEA itself. It was not until the largest fertility support group of the UK brought patients' views together their voices were heard.

Bringing patients' views together

Following the removal of donor anonymity, while hundreds of fertility patients were protesting the new policy through various online patient support networks, a fertility travel survey conducted by INUK (Infertility Network UK) in 2008 brought these opinions together for the first time.²³ INUK had 339 responses to its survey, which explored patient experiences of cross-border treatment. The results were striking: 76 per cent of respondents stated that they would consider going abroad for treatment (in particular, to receive egg donation). Further, 120 of the 339 (35 per cent) respondents answered the question “Which country did you go to for your treatment?”; the most popular response was Spain, which maintains the donor anonymity for fertility treatment. At least three times as many patients went there as anywhere else.

Although the INUK study received little recognition by public bodies, its findings were confirmed by the European Society of Human Reproduction and Embryology (ESHRE) Task Force, which undertook the most comprehensive study on cross border reproductive care to-date. The ESHRE survey contained data from 46 clinics across Europe, including 53 patients travelling from the UK. 34 per cent of UK resident patients – more than any other nationality within Europe – cited access issues as their reason for travelling abroad.²⁴

Findings from a recent qualitative study of UK residents showed that the four most commonly cited reasons for travel were: donor shortages in the UK (27 cases), cost (13 cases), perceived better success rates overseas (12 cases) and previous unsatisfactory care in the UK (7 cases). Overall, ‘a desire for timely and affordable treatment with donor gametes’ was evident in 71% of cases, making donor conception the most sought after treatment by the CBRC travellers. Most patients sought treatment within European borders, the most popular destinations being Spain and Czech Republic.²⁵

The growing evidence around reproductive tourism led the HFEA to move away from solely administering warnings, to critical engagements with its policy. In August 2010, the Authority launched a full, public consultation into sperm and egg donation policies. In the consultation document, the HFEA noted that the landscape of donation had changed since the Authority looked at their rules in 2005, and it emphasized that it would like to update these if

²³ The Infertility Network UK Fertility Tourism Survey Results (Infertility Network: Bexhill-on-Sea 2008).

²⁴ Shenfield (n 9)

²⁵ L Culley et al, 'Crossing Borders for Fertility Treatment: Motivations, Destinations and Outcomes of UK Fertility Travellers' (2011) 26 Human Reproduction 2373.

necessary. It was acknowledged that the demand for donor treatment in the UK was greater than the supply of donors and that the removal of donor anonymity might have exacerbated the shortage. The Authority further noted that the shortage of donors resulted in long waiting times for treatment, with reports of UK waiting times of three to five years for donor eggs. Concerns were also expressed that some fertility centres overseas may offer substandard treatment, and that increasing numbers of people are purchasing unscreened sperm on the Internet.²⁶ The HFEA asked if gamete supply could be improved by a change in policy, or withdrawal from commitments under the EUTCD.²⁷

The HFEA received a record number of responses to its consultation, with over 2400 surveys completed by around 1100 people. The first set of decisions made by the Authority in response was that the maximum number of families that an individual donor can donate to should not be changed. The HFEA also decided to issue guidance stating that sperm and eggs should not be mixed if they come from very close genetic relatives. Further, the allowable compensation amounts for gamete donors have been increased: Egg donors can now receive £750 per cycle of donation, whilst sperm donors can receive a £35 fee per individual visit to a clinic.²⁸ Finally, the HFEA decided to take a more proactive approach to donor recruitment and established a National Donation Strategy Group. Chaired by Professor Sheila McLean, the Group will bring together a wide range of experts in order to enhance the information that donors receive, develop new approaches to raising awareness of donation, and ascertain how the care of donors can be improved. However, it is questionable whether any of these measures can improve the UK's donor conception policy in terms of its acceptability to users, unless stakeholders' views are central to the HFEA's policy decisions.

Conclusion

The virtual ethnography study presented in this chapter offers some potentially important insights into how would-be parents negotiate the issues of donor gamete donation

²⁶ HFEA, 'A Review of the HFEA's Sperm and Egg Donation Policies' (HFEA 2011) <http://www.hfea.gov.uk/docs/2011-01_13_Donation_review_background.pdf> accessed 23 May 2012.

²⁷ E Blyth, 'Gamete Donation Review: Not the HFEA's Finest Hour' (Bionews 605, 2011) <http://www.bionews.org.uk/page_94012.asp> accessed 23 May 2012.

²⁸ S Starr, 'HFEA Takes First Set of Decisions Following Donation Review' (BioNews 616, 2011) <http://www.bionews.org.uk/page_102199.asp> accessed 8 May 2012.

interactively and collectively on discussion boards. The topics generated by users of *Repromed* provide an indication of those matters they perceive as important or problematic with regards to donation. The most important issue that users raise is that, despite the warnings of a likely donor shortage, the government lifted anonymity at the expense of would-be parents' access to treatment, and the HFEA should have taken measures to avoid the (predicable) crisis that resulted from this legislative shift.

The continued shortage of donor gametes means that UK patients have to wait longer for treatment and have less choice with respect to donor characteristics. In response, we can see, via discussion threads about fertility travel and online sperm providers, that would-be parents have come to experiment with new ways of contesting the law, and - more importantly - novel means of avoiding it. The user accounts indicate that donor shortage problems lead couples to find alternative solutions to their childlessness; in particular, would-be parents in the UK have readily available alternatives in their access to treatment in other EU nations. Success rates, the lower cost of treatment, donor availability, and anonymity make clinics abroad increasingly attractive. Yet, the HFEA warn against their use, creating further frustration.

The posts on the patient forums that I presented here suggest that patients feel their views are ignored by the HFEA in policy-making. But there is little they can do to have their voices heard without compromising their anonymity. Furthermore, the pursuit of a child is, to many would-be parents, a considerably demanding task: physically, emotionally, and in terms of time. Little space remains for lobbying when pregnancy is still to be achieved. Finally, being a would-be parent is a transitional phase: once pregnant, individuals' priorities might change, and campaigning for new policy to address the needs of others is less salient once one's own needs have been met.

It is important at this point to clarify that I am not claiming that would-be parents are completely divorced from more influential policy actors and processes. Indeed, patients use online environments to make their voices audible to policy-makers: they participate in online surveys, connect with journalists and researchers who recruit interviewees, and sign electronic petitions. However, in effect, UK would-be parents are caught in a double bind: those who are directly affected by the legal shift may be reluctant to press their claims because confidentiality matters to them. Given this reticence, their voices are not taken into consideration by public bodies, like the HFEA.

Since the passing of the Act 1990, some academic and political commentators have questioned whether the regulatory model adapted for the HFEA was acceptable to the

general public, or to the major stakeholders, those who are directly affected by the law.²⁹ Subsequently, the HFEA has faced several legal challenges and its policy decisions were criticised by the House of Commons Science & Technology Committee: “democracy is not served by unelected quangos taking decisions on behalf of Parliament authorisation”³⁰. In one of these legal challenges in 2004, the Court of Appeal confirmed that the HFEA had the legal authority to regulate these areas: “Parliament has placed that choice in the hands of the HFEA”.³¹ But how does the HFEA make these choices? During the public debate over ending donor anonymity it was clear that the proposed legal shift would create a donor crisis, and as a result, fewer people would have access to treatment. But the would-be parents’ interests were not a paramount concern to the Authority. The then chair of the HFEA made it clear that she viewed the principal of the welfare of the child as fundamental, despite the fact that the HFE Act only requires that this should be ‘taken into account’.³²

As Dawson argues, the HFEA’s inspector role is vital to ensure the clinics are fully licensed and monitored.³³ On the other hand, the recent consultation might be an opportunity to separate or improve the Authority’s approach to policy-making. Arguably, the UK assisted conception regulations may benefit from a more democratic decision-making process where the ‘conflicting’ interests of the stakeholders are fully and equally taken into account. This might include more evidence-based policy making, and taking full advantage of the Internet and information technology to enhance stakeholder participation especially to reach out those who cannot use transparent and formal modes of communication due to their confidentiality concerns, like the would-be parents in this study.

Finally, it should be noted that the passage of the Public Bodies Act 2011 made it possible to transfer the functions of quangos (including the HFEA and Human Tissue Authority) elsewhere, without opening up the original Act that created them.³⁴ The HFEA is one of several quangos set to be abolished, in order to meet the UK Government’s aim of cutting National Health Services (NHS) costs. On 28 June 2012 the government launched a

²⁹ T Callus, ‘Patient Perception of the Human Fertilisation and Embryology Authority’ (2007) 15 Medical Law Review 62.

³⁰ *Developments in Human Genetics and Embryology*, House of Commons Science and Technology Committee Report, 2002, para 18.

³¹ *R (on the application of J. Quintavalle on behalf of CORE) v. Human Fertilisation and Embryology Authority*, [2004] Q.B. 168

³² Dawson (n 33) (3)

³³ Dawson (n 33)

³⁴ Public Bodies Act 2011 (c. 24) Section 5

consultation on the future of the HFEA to consider whether the regulators' responsibilities should move to the Care Quality Commission (CQC) and the Health Research Authority (HRA).³⁵ Consequently, the likelihood of current HFEA deliberations into mechanisms to increase donation being successfully translated into practice is unclear. Regardless, it is clear that future efforts to govern the interactions between law, biomedical knowledge and reproductive practice keep in mind the limitations of authority and the creativity of subjects, and endeavour to seek solutions that satisfy the hopes and aims of both regulators and regulatees in democratically-defensible ways.

³⁵ HFEA, 'Consultation on Proposals to Transfer Functions from the Human Fertilisation and Embryology Authority and the Human Tissue Authority' (HFEA 2012) < <http://www.dh.gov.uk/health/2012/06/consultation-regulators>> accessed 4 July 2012.